# Negative labeling and social exclusion of people living with human immunodeficiency virus/acquired immune deficiency syndrome in the antiretroviral therapy era: insight from attitudes and behavioral intentions of female heads of households in Zambézia Province, Mozambique

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# Negative labeling and social exclusion of people living with human immunodeficiency virus/ acquired immune deficiency syndrome in the antiretroviral therapy era: insight from attitudes and behavioral intentions of female heads of households in Zambézia Province, Mozambique

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In the age of antiretroviral therapy (ART), unraveling specific aspects of stigma that impede uptake and adherence to human immunodeficiency virus (HIV) services and the complex intersections among them might enhance the efficacy of stigma-reduction interventions targeted at the general public. Few studies have described community stigma in high HIV prevalence regions of Mozambique where program scale-up has been concentrated, but fear of stigma persists as a barrier to HIV service uptake. Principal components analysis of attitudinal data from 3749 female heads of households surveyed in Zambézia Province was used to examine patterns of agreement with stigmatizing attitudes and behavior toward people living with HIV. Inferences were based on comparison of factor loadings and commonality estimates. Construct validity was established through correlations with levels of knowledge about HIV transmission and consistency with the labeling theory of stigma. Two unique domains of community stigma were observed: negative labeling and devaluation (NLD, $\alpha = 0.74$) and social exclusion (SoE, $\alpha = 0.73$). NLD is primarily an attitudinal construct, while SoE captures behavioral intent. About one-third of the respondents scored in the upper tertile of the NLD stigma scale (scale: 0–100 stigma points) and the equivalent was 41.3% in the SoE stigma scale. Consistent with literature, NLD and SoE stigma scores were inversely correlated with HIV transmission route knowledge. In item level analysis, fear of being labeled a prostitute/immoral and of negative family affect defined the nature of stigma in this sample. Thus, despite ART scale-up and community education about HIV/acquired immune deficiency syndrome (AIDS), NLD and SoE characterized the community stigma of HIV in this setting. Follow-up studies could compare the impact of these stigma domains on HIV services uptake, in order to inform domain-focused stigma-reduction interventions.

**Keywords:** community stigma; HIV/AIDS knowledge; household survey; rural Mozambique

## Introduction

Stigma causes suffering among people living with human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) (PLWHA) (Mahajan et al., 2008; Maughan-Brown, 2010) and those who are not infected with HIV but worry about infection and its social consequences (Alonzo & Reynolds, 1995; Onye-wadume, 2008). Knowledge about HIV transmission and treatment, experience with HIV infection, and treatment efficacy beliefs (all associated with increased access to HIV education programs) tend to reduce community stigma via rebuff of erroneous beliefs, the realization that people with HIV are the same as everybody else, and that HIV infection is not necessarily life threatening. However, fear of community stigma persists as a barrier to

HIV services uptake worldwide (Carrizosa et al., 2010; Ekstrand, Bharat, Ramakrishna, & Heylen, 2012; Li et al., 2012; Monjok, Smesny, & Essien, 2009; Smith & Baker, 2012; Surkan et al., 2010; Turan et al., 2010) despite the scale-up of HIV treatment programs (Maughan-Brown, 2010) and stigma-reduction initiatives (Sengupta, Banks, Jonas, Miles, & Smith, 2011).

Unraveling specific aspects of stigma that impede uptake and adherence to HIV services in the age of antiretroviral therapy (ART) and the complex intersections among them might enhance the efficacy of stigma-reduction interventions. Data from a general household survey were used to identify key domains of community stigma in a rural region of Mozambique with sub-regional differences in exposure to HIV treatment interventions.

## Methods

### Background

The *Ogumaniha*-SCIP baseline survey, conducted in 2010, recruited 3749 female heads of households in 259 randomly selected enumeration areas across 14 districts in Zambézia Province, Mozambique. The survey questionnaire included a module on HIV knowledge and stigma. Details about this survey are given elsewhere (Vergara et al., 2011).

### Measurement of stigma and HIV knowledge

Stigma items were adapted from a questionnaire used by Pulerwitz, Michaelis, Lippman, Chinaglia, and Diaz (2008). The questionnaire lists 15 items that a respondent endorses on a 4-point Likert scale from "strongly disagree" to "strongly agree." The statements reflect labels and stereotypes that devalue and reduce a person with HIV to a tainted and socially undesirable status (Earnshaw & Chaudoir, 2009; Goffman, 1963; Mahajan et al., 2008) and specific discriminatory actions against PLWHA (Table 2). Modifications were made to adapt the survey to heads of households. Items were scored such that higher scores denoted greater stigmatization. Thus, the social exclusion (SoE) items shown in Table 2 were reverse scored to reflect greater stigma.

*HIV transmission knowledge* was measured by answers to questions about adult-to-adult and mother-to-child transmission routes. A summative score (range: 0–10 points) was generated such that higher scores indicated greater knowledge.

### Statistical methods

R-software 2.13.1 (www.r-project.org) was used for statistical analyses. Analysis scripts are available at http://biostat.mc.vanderbilt.edu/ArchivedAnalyses. Ethical approval for secondary data analysis was provided by the Vanderbilt University (IRB#121003).

*Principal component analysis* (PCA) of stigma items was conducted to identify dimensions of community stigma they represent. Orthogonal varimax rotation was chosen to minimize overlap in item loading across dimensions, generating uncorrelated dimensions of stigma. In PCA, factor loadings indicate the correlation between the observed variable (i.e., item) and the latent variable (i.e., dimension) and the magnitude of the contribution that the observed variable makes to the meaning of the latent variable. Uniqueness shows the fraction of variance in the observed variable that is not explained by the latent variable (UCLA Academic Technology Services, 2006). Scales for each dimension were calculated by taking the mean value of non-missing items and then normalized to a 0–100 range. Decision criteria were primarily the factor loadings and uniqueness estimates. Internal reliability, a measure of the extent to which items in each dimension hang together as a group, was evaluated via Cronbach's alpha coefficients (typically, $\alpha \geq 70$ denotes acceptable reliability).

*Construct validity of stigma dimensions*, a measure of the extent to which a scale measures what it is intended to measure, was established by correlating each stigma scale estimate with the estimated level of HIV transmission knowledge. The correlation between stigma and HIV knowledge has been used as criterion for the construct validity of stigma scales (Feyissa, Abebe, Girma, & Woldie, 2012; Nyblade, 2006). Our stigma scales would be valid if greater HIV transmission knowledge correlated with lower endorsement of stigma. Additional validity was gaged via resemblance with dimensions associated with the labeling theory of stigma (Mahajan et al., 2008) and reported in relatable settings (Feyissa, Abebe, Girma, & Woldie, 2012; Holzemer et al., 2007; Maughan-Brown, 2010; Nyblade, 2006).

## Results

Table 1 (column 1) lists the *characteristics of the study population*. Of the 3749 respondents 3323 had data on stigma. Respondents missing stigma data ($n = 426$) did not differ from those with data by HIV knowledge and other important variables of interest.

*PCA* yielded two stigma dimensions (Table 2). Cronbach's alphas for Dimension 1 and Dimension 2 were 0.74 and 0.73 respectively, explaining 94.7% of the variance. These Cronbach's alphas are comparable to those reported by Pulerwitz et al. (2008) (i.e., $\alpha = 0.76$ for the combined 15-item scale). Dimension 1 comprised nine items. Based on factor loadings and uniqueness estimates (Table 2), believing that "almost all PLWHA are prostitutes or sexually immoral" contributes the most to the meaning of Dimension 1. The next greatest contributor is preparedness to sever the relationship with a friend who becomes HIV positive, followed by thinking that PLWHA should be marked and then that people in general will avoid you if you had AIDS. Dimension 1 was deemed to be consistent with negative labeling/stereotyping and anticipation of devaluation by others if one became HIV-infected. Hence Dimension 1 was labeled "negative labeling and devaluation" (NLD: mean = 39 points, SD = 17.6). Dimension 2 comprised six items that predominantly assessed participants' willingness to support and interact with PLWHA. The latent variable among items in Dimension 2 (Table 2) was deemed to be willingness to care for friends, family, and neighbors but a distrust of others' willingness to do the same to you. When Dimension 2 is rescaled so that higher scores indicate greater stigma, it depicts the endorsement of "social exclusion" (SoE: mean = 47, SD = 25.7).

As shown in Table 1, 34.1% of the respondents scored in the upper tertile (mean $\geq 66.67$ on a 100-point scale) of

Table 1. Characteristics of the female heads of households by tertiles of NLD and SoE stigma scores.

| | Total | NLD (n = 3219) | | | | SoE (n = 3271) | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | 1st tertile | 2nd tertile | 3rd tertile | P-value | 1st tertile | 2nd tertile | 3rd tertile | P-value |
| Sample N (%) | 3323 | (37.7) | (27.2) | (34.1) | | (20.8) | (37.9) | (41.3) | |
| Age (years), median (IQR) | 28 (23–36) | 28 | 29 | 28 | 0.057 | 26 | 29 | 29 | 0.162 |
| Education (years), median (IQR) | 2 (0–4) | 2 | 2 | 2 | 0.211 | 2 | 2 | 2 | 0.017 |
| Distance of EA from health facility (km), median (IQR) | 6.2 (3.2–10.3) | 6.6 | 6.2 | 6.2 | 0.012 | 5.8 | 6.2 | 7.6 | <0.001 |
| Geographically isolated district, % (95% CI) | 56.4 (43.1, 69.7) | 58.6 | 50.1 | 58.1 | <0.001 | 69.0 | 45.8 | 55.5 | 0.704 |
| Respondent understands Portuguese, % (95% CI) | 42.0 (35.3, 48.8) | 39.8 | 43.5 | 43.9 | 0.324 | 39.0 | 44.8 | 40.6) | 0.011 |
| Marital status, % (95% CI) | | | | | 0.587 | | | | 0.275 |
|    Married/common law | 74.5 (70.9, 78.0) | 73.5 | 74.1 | 76.0) | | 78.6 | 73.5 | 68.9 | |
|    Divorced/separated | 3.7 (1.6, 5.9) | 2.6 | 7.5 | 2.4 | | 5.6 | 3.2 | 2.7 | |
|    Single | 17.0 (13.6, 20.5) | 18.7 | 15.3 | 16.2 | | 10.7 | 18.1 | 25.0 | |
|    Widowed | 4.8 (2.6, 7.0) | 5.2 | 3.1 | 5.4 | | 5.0 | 5.2 | 3.4 | |
| Religion, % (95% CI) | | | | | <0.001 | | | | 0.012 |
|    Catholic | 47.7 (41.3, 54.0) | 43.4 | 51.1 | 50.8 | | 41.3 | 53.7 | 49.6 | |
|    Protestant | 12.7 (9.4, 16.1) | 18.2 | 8.7 | 8.5 | | 14.8 | 13.4 | 12.1 | |
|    Evangelical and Pentecostal | 16.6 (11.7, 21.6) | 15.4 | 17.2 | 17.9 | | 18.6 | 10.9 | 17.2 | |
|    Other Christian | 4.4 (1.4, 7.4) | 3.8 | 4.5 | 5.0 | | 6.6 | 3.1 | 4.0 | |
|    Muslim | 9.0 (5.4, 12.5) | 10.5 | 7.6 | 7.8 | | 10.5 | 9.3 | 6.8 | |
|    Non-Christian Eastern | 2.1 (1.1, 3.1) | 1.3 | 3.8 | 2.0 | | 1.9 | 3.3 | 1.1 | |
|    Other | 7.5 (5.0, 10.0) | 7.4 | 7.0 | 8.0 | | 6.2 | 6.2 | 9.1 | |
| HIV knowledge (score) (n = 3219) | 3 (0–4) | 3 | 3 | 2 | <0.001 | 3 (1–5) | 3 (1–4) | 2 (0–4) | <0.001 |
| HIV infection of self, relative, and/or friend, % (95% CI) | 12.5 (7.8, 17.3) | 13.0 | 12.2 | 12.2 | 0.108 | 16.5 | 11.5 | 8.8 | <0.001 |
| Accessed VCT facility, % (95% CI) | 20.3 (15.1, 25.6) | 23.2 | 19.6 | 17.3 | 0.375 | 29.6 | 15.8 | 16.6 | <0.001 |
| Accessed health facility (%, n = 3219) | 76.9 (72.6, 81.2) | 77.7 | 81.1 | 72.8 | 0.939 | 80.8 | 75.0 | 72.6 | <0.001 |
| Perceived chance of becoming infected with HIV, % (95% CI) | | | | | 0.073 | | | | <0.001 |
|    Don't know | 47.8 (42.2, 53.3) | 47.7 | 41.1 | 52.6 | | 49.1 | 39.7 | 56.1 | |
|    No chance | 24.5 (20.7, 28.4) | 25.2 | 29.2 | 20.4 | | 18.4 | 28.9 | 25.7 | |
|    Small chance | 19.8 (16.2, 23.3) | 18.3 | 24.1 | 18.6) | | 20.5 | 24.8 | 12.9 | |
|    Good chance | 5.7 (4.0, 7.4) | 6.6 | 4.0 | 5.7 | | 8.2 | 5.6 | 3.9 | |
|    Already infected | 2.2 (1.1, 3.3) | 2.2 | 1.6 | 2.8 | | 3.8 | 1.0 | 1.4 | |
| Income, median (IQR) | 300 (0–700) | 300 | 150 | 300 | 0.011 | 300 | 286 | 150 | <0.001 |

Notes: Continuous variables are reported as weighted estimates of median (IQR), with each observation being weighted by the inverse of the household sampling probability.
Categorical variables are reported as weighted percentages, with each observation being weighted by the inverse of the household sampling probability. The 95% confidence intervals include precision estimates that incorporate the effects of stratification and clustering.
EA: enumeration area; VCT: voluntary counseling and testing; IQR: interquartile range.
"Other Christian" includes LDS Mormon and Jehovah's Witness. "Other" includes spiritual, traditional religions, and agnostic or atheist.
Tests of association with stigma scale (continuous) include Spearman's rank correlation (continuous) and rank sum test (categorical).

Table 2. Stigma scales and their reliability coefficients.

| Description | Factor loading | Uniqueness | Mean (SD) | Cronbach's alpha ($\alpha$) |
|---|---|---|---|---|
| *Factor 1: Negative labeling and devaluation* | | | 39.1 (17.6) | 0.742 |
| A person who has AIDS should not be allowed to work with other people to protect the people who do not have AIDS. | 0.454 | 0.786 | | |
| A person who has AIDS should not be allowed to make food to sell (to be consumed by other people). | 0.446 | 0.783 | | |
| AIDS is a punishment for bad behavior. | 0.416 | 0.810 | | |
| AIDS is a punishment from God. | 0.484 | 0.759 | | |
| People with HIV/AIDS should be marked so everyone could identify them. | 0.524 | 0.719 | | |
| Almost all people who have HIV/AIDS are prostitutes or sexually immoral. | 0.596 | 0.644 | | |
| If you learned that a friend of yours had AIDS, you would stop being their friend. | 0.567 | 0.671 | | |
| If you told your regular partner that you have HIV/AIDS, s/he would leave you. | 0.472 | 0.735 | | |
| If you had AIDS, people would avoid you | 0.511 | 0.716 | | |
| *Factor 2: Social inclusion/exclusion* | | | 46.9 (25.7) | 0.731 |
| It is better not to hide that you have AIDS, so you can get support from friends or family. | 0.537 | 0.706 | | |
| You would feel comfortable living closely with someone who has HIV/AIDS | 0.608 | 0.627 | | |
| You would be willing to care for a relative with AIDS in your house/home. | 0.666 | 0.555 | | |
| If you saw someone with HIV/AIDS being mistreated, you would try to help him or her. | 0.519 | 0.716 | | |
| It is safe to let your child play with children who have HIV/AIDS. | 0.586 | 0.644 | | |
| You would worry about touching someone with HIV/AIDS. | 0.533 | 0.700 | | |

Note: Answers were coded 1–4 with highest stigma as 4. Thus, for factor 2 items a score of 4 indicates the strongest disagreement with the statement. Each scale is the mean score of all non-missing items, normalized to range 0–100.
$\alpha$ = Cronbach's alpha, a measure of the reliability of the factor/scale based on the internal consistency of the constituent items.

the NLD scale and the equivalent was 41.3% in the SoE scale. The mean for each stigma dimension was <50 points, suggesting moderate-to-low intensity of stigma (Table 2). Regardless of the stigma dimension considered, high knowledge of HIV transmission correlated with lower endorsement of stigma (Table 3). In unadjusted analysis (Table 1) years of education was associated with SoE and not with NLD stigma. In adjusted analysis (Table 3) there was no significant relationship between education and stigma. Other significant relationships were with religion and health facility contact variables (i.e., distance from and use of voluntary counseling and testing (VCT) and government health facilities).

## Discussion

The correlation between stigma and HIV transmission knowledge is consistent with global literature (Herek, Capitanio, & Widaman, 2002; Lau & Tsui, 2005; Tee & Huang, 2009). Criteria for construct validity and internal reliability were met for both stigma dimensions. Item distribution between the two dimensions is consistent with literature on "othering" (Johnson et al., 2004; Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006) in which more negative affect is directed at the

distant than the relatable "other." The NLD stigma, characterized in keeping with labeling theory (Mahajan et al., 2008), is similar to the stigma dimension labeled "values based stigma" (Feyissa et al., 2012). Findings are consistent with literature which distinguishes symbolic stigma (encompassing negative stereotypes and labels) from instrumental stigma (mainly fear of contagion) (Ekstrand et al., 2012; Mahajan et al., 2008). The primary fear among this population is to be labeled a prostitute or an immoral, and less than that of a casual contagion. This could be because respondents are all female and such labels might be the aspect of stigma that is most salient to them (Bunting, 1996). Improved knowledge about HIV transmission might also account for such nuanced differences. Lack of association with years of education suggests the significance of HIV-specific as opposed to generic knowledge. Additionally, contact with health facilities and religion might also impact the manner in which these dimensions of stigma are endorsed. The domain specificity of these relationships needs to be investigated further.

Study limitations include the cross-sectional design and lack of prior published data on community stigma in this setting. Given positive impacts of scaling up HIV treatment and public education campaigns on levels

Table 3. Association between community stigma scales and knowledge of HIV transmission adjusted for demographic and healthcare contact variables.

| | NLD stigma Beta estimate (95% CI) | *P*-value | SoE stigma Beta estimate (95% CI) | *P*-value |
|---|---|---|---|---|
| HIV knowledge score | | <0.001 | | <0.001 |
| 0 | −1.10 (−3.04, 0.83) | | 3.93 (1.82, 6.03) | |
| 2 (ref) | 0 | | 0 | |
| 4 | −1.22 (−2.81, 0.37) | | −1.03 (−2.85, 0.80) | |
| 6 | −3.92 (−5.99, −1.84) | | −3.39 (−5.71, −1.07) | |
| Age (per 5 years) | 0.02 (−0.28, 0.32) | NS | 0.08 (−0.37, 0.52) | NS |
| Education (per 5 years) | −0.29 (−1.80, 1.21) | NS | 0.78 (−1.21, 2.77) | NS |
| Distance to clinic (per 1 km) | −0.13 (−0.31, 0.04) | NS | 0.13 (−0.04, 0.30) | NS |
| Isolated district | −1.20 (−3.32, 0.93) | NS | −2.88 (−5.29, −0.46) | .019 |
| Understands Portuguese | 0.46 (−0.98, 1.90) | NS | 0.18 (−1.67, 2.03) | NS |
| Marital status | | NS | | NS |
| Married/common law (ref) | 0 | | 0 | |
| Divorced or separated | −1.50 (−4.74, 1.75) | | 1.04 (−3.40, 5.48) | |
| Single | −1.41 (−3.29, 0.46) | | 1.04 (−1.10, 3.18) | |
| Widowed | 0.64 (−1.90, 3.19) | | −2.73 (−5.64, 0.17) | |
| Religion | | .002 | | .034 |
| Catholic (ref) | 0 | | 0 | |
| Protestant | −3.26 (−5.74, −0.78) | | 0.79 (−1.97, 3.55) | |
| Evangelical and Pentecostal | −0.31 (−2.32, 1.70) | | −0.50 (−3.13, 2.13) | |
| Other Christian | −3.60 (−6.68, −0.52) | | 1.81 (−1.91, 5.54) | |
| Muslim | 1.68 (−0.52, 3.88) | | −4.17 (−6.80, −1.54) | |
| Non-Christian Eastern | −0.13 (−4.25, 3.97) | | 1.99 (−3.48, 7.46) | |
| Other | 0.96 (−2.04, 3.97) | | −1.50 (−4.56, 1.55) | |
| Income (per 500 MT) | 0.15 (−0.09, 0.39) | NS | 0.18 (−0.50, 0.14) | NS |
| HIV infection of self, relative, and/or friend | 2.04 (−0.42, 4.50) | NS | −3.17 (−5.78, −0.56) | .017 |
| Accessed VCT | −2.45 (−4.22, −0.68) | .007 | −0.39 (−2.58, 1.80) | NS |
| Accessed health facility | 0.31 (−1.35, 1.97) | NS | −3.64 (−5.42, −1.86) | <.001 |

Note: NS = not significant (*p* > 0.1).

of HIV/AIDS knowledge in the community (Sengupta et al., 2011), longitudinal studies are needed to document changes in community stigma over time. A survey instrument with more stigma items might have yielded additional and different dimensions of stigma than the two captured here. While high alpha estimates facilitated the grouping of variables, most factor loadings were moderate to weak (Table 2). For example, Dimension 1 is less likely explained by the view that "AIDS is a punishment for bad behavior" or that "A person who has AIDS should not be allowed to work with other people to protect the people who don't have AIDS" because of low factor loadings and high uniqueness of these items. Thus, some of the current items need modification in future research.

## Conclusion

Our data indicate willingness to negatively label and exclude PLWHA (albeit moderate) in a rural community that has experienced expansion in HIV prevention and treatment services. Follow-up studies could compare the impact of SoE vs. NLD on HIV services uptake, in order to inform domain-focused stigma-reduction interventions. Unraveling complex intersections among these aspects of public attitudes/behavior might further enhance the efficacy of stigma-reduction interventions targeted at the general public.

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